

Nebraska's New Program to Prevent Birth Defects

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WITH THE ENACTMENT of Legislative Bill 1203, the State of Nebraska created the birth defects prevention program. This legislative measure, which became effective July 6, 1972, was originated to aid in reducing the occurrence of malformations or inherited diseases. It recognizes that a congenital anomaly is not only a tragedy for the child and the family, but also a matter of vital concern to public health. The Nebraska Department of Health has the responsibility for the development and implementation of scientific investigations and educational programs on the causes, methods of prevention, treatment, and cure of birth defects.

An important aspect of the prevention program is the establishment of a birth defects registry, which was initiated in May of 1973. Using data supplied by Nebraska's physicians and hospitals, this registry will keep close surveillance on the occurrence and frequencies of various birth defects in Nebraska. The data are currently being submitted to the Center for Disease Control, Public Health Service, in Atlanta, Ga., for computer interpretation and analysis. The results are published bimonthly by the Center. The coded data will be available to any qualified investigator who wishes to use them for survey or research purposes. When sufficient baseline information has been

obtained, it is anticipated that the registry will be useful for signaling the occurrence of previously undetectable epidemics or clusters of birth defects.

A major portion of the program is carried out by the Human Genetics Laboratory at the University of Nebraska Medical Center in Omaha. The medical center's responsibilities include statewide professional education, training, service, and research in various aspects of birth defects prevention. The full resources of the medical center, as well as those of Omaha's Creighton Medical School and health professionals throughout the State, are available to assist in carrying out the program.

Educational services in progress in-

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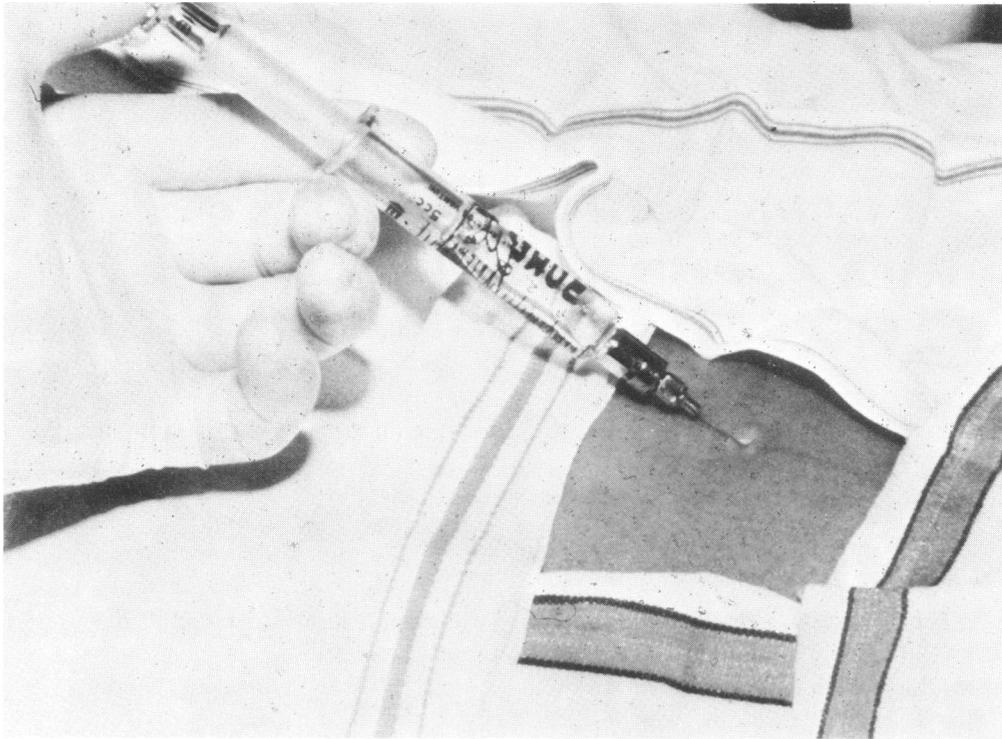


Figure 1. Obstetrician prepares woman in fourth month of pregnancy for amniocentesis

clude workshops, conferences, displays, and talks to health professionals. One avenue being used to educate health professionals is telephone conference calls. A network of conference telephones reaches 37 hospitals throughout the State and serves physicians and nurses who further their education by listening to experts in medicine and science discuss various means to prevent birth defects. Topics covered in the conference calls have included "Rubella vaccine and RhoGam," "Genetic counseling," "In utero detection of genetic defects," and "Amniocentesis." A workshop in human cytogenetics has been designed to acquaint physicians and registered medical technologists throughout Nebraska with recent advances in "chromosomology," tissue culture techniques, and prenatal detection of birth defects. Displays and scientific talks to health professionals on the goals and scope of the birth defects prevention program are incorporated into medical societies' meetings and conventions whenever possible. The Nebraska Department of Health is carrying out a concurrent program of health education to emphasize

and explain the various aspects of the prevention program to the general public.

The birth defects prevention program is adopting many new technological advances in providing the services to attain its goals. Incorporated in these goals is provision for a prenatal diagnostic service to all physician-referred pregnant women who have previously given birth to a genetically abnormal child or who have a family history of a genetic disorder. This service is also provided to rule out Down's syndrome in the fetus of expectant mothers over the age of 35, in recognition that the chance of having such a child increases significantly with the age of the mother. This probability is well illustrated in a recent study reported by Boardman and Jennett revealing that the rate of mongoloid children born to mothers age 35 or older is more than 40 times the rate for mothers under age 35 (1).

Prenatal diagnosis involves amniocentesis; that is, the withdrawing of 10 to 20 cc of amniotic fluid from the uterus of the expectant mother, at about 12-16 weeks of pregnancy (fig. 1). This pro-



Figure 2. Laboratory technologist changes growth media for fetal cells obtained through amniocentesis

Figure 3. Laboratory technologist checks growth of fetal cells obtained by amniocentesis



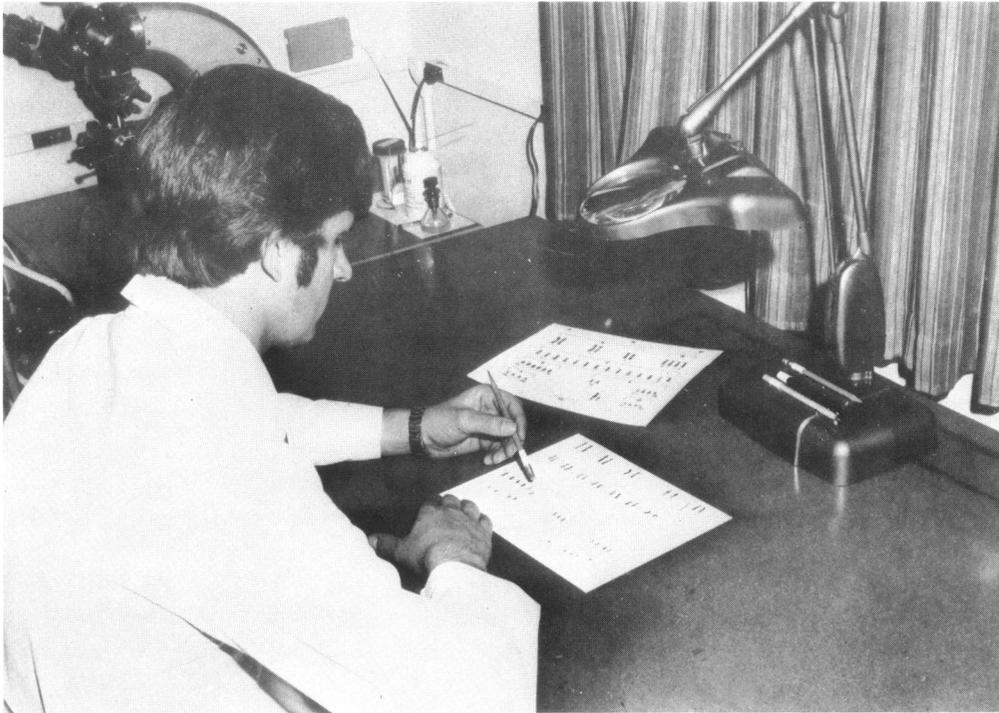


Figure 4. Research technologist works with chromosomes for prenatal detection of Down's syndrome

cedure, while relatively safe at this stage, must be done by physicians who are highly trained in the technique. Fetal cells are isolated from the fluid and, after sufficient growth and multiplication (figs. 2 and 3), are analyzed to detect a suspected abnormality.

Approximately 55 different genetic abnormalities can be diagnosed in the fetus by this procedure (2). Some of these conditions, when detected, may be treatable; others are still the subject of research. An example of one of the latter conditions is Down's syndrome, or mongolism. The most common single genetic type of mental retardation, mongolism occurs in approximately 1 out of every 600 live births, which in Nebraska would indicate 40 new cases each year. This condition is now detectable in the fetus. Figure 4 illustrates a phase of chromosome analysis being done to rule out mongolism in fetal cells obtained by amniocentesis. No treatment is as yet available for the condition.

Genetic counseling for birth defects and allied diseases is also available under the birth defects prevention program.

Counselors in this service attempt to answer many questions parents or relatives of an affected child may have, such as, "What are the chances of it happening again?" To state the probability of re-occurrence in a subsequent child may require diagnostic studies, review of the medical records of affected relatives, chromosome analysis, and study of the family history and statistics on the occurrence of a specific defect in large populations.

With the advent of the birth defects prevention program, it is hoped that the incidence of birth defects will be reduced and that new discoveries will be made in this field with even greater ability to alleviate suffering and to improve public health.

REFERENCES

- (1) Boardman, R. E., and Jennett, R. J.: Mongoloid births: age of mother. Commission on Professional and Hospital Activities 9: 1-3, Aug. 23, 1971.
- (2) Seegmiller, J. E.: New prospects for understanding and control of genetic diseases. Arch Intern Med 130: 181-185, August 1972.